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Aging Adults With Intellectual Disabilities

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THE POPULATION OF OLDER ADULTS IN THE UNITED States is projected to reach 70 million within the next 20 years.¹ Increasing age is but one of many factors associated with disparities in health access and outcomes, along with sex, nonwhite race, lower socioeconomic status, geographic proximity to health professionals, and having a disability. Moreover, within the population of those with disabilities, persons with intellectual disabilities (ID) are further disadvantaged.² The potential synergistic effect of increasing age with concomitant membership in a vulnerable population increases the risk of experiencing poor health.

Owing to marked increases in life expectancy for individuals with ID in recent decades, life expectancy of adults with mild ID is rapidly approaching near parity with the general population.³ Persons with moderate or severe ID now routinely live into their late 60s and late 50s, respectively.³ Furthermore, older adults with Down syndrome are consistently living beyond their late 50s,⁴ with sporadic reports of individuals living to their 70s and even early 80s. Consequently, the relatively rapid increase in a new population of aging adults with complex medical and mental health problems has resulted in inadequate geriatric health care provision.

Aging with ID presents significant challenges, the breadth and scope of which are only beginning to be understood. As older adults with ID achieve old age, they experience physical aging changes and age-related chronic diseases common to the general older population. However, proper identification and management of disease and physical disability related to aging remains an unmet need. Literature summaries continue to report consistently higher rates of morbidity and mortality in adults with ID, as well as highly prevalent but frequently unrecognized or poorly managed health conditions such as vision and hearing impairments, obesity, epilepsy, skin conditions, dental pathology, behavioral/mental health problems, gastrointestinal conditions, and need for long-term polypharmacy.^{5,6}

While the burden of increased comorbid conditions cuts across the population of adults with ID as a whole, the complexity of appropriate surveillance of medical

care is further complicated by the diversity of syndrome-specific aging issues. The older adult with Down syndrome, for example, experiences a phenomenon of accelerated aging, characterized by increased rates of cataracts, hearing loss, hypothyroidism, osteoporosis, epilepsy, sleep apnea, and a genetically elevated risk of developing Alzheimer disease. Older adults with cerebral palsy (who often have ID) are at greater risk of accelerated musculoskeletal system aging, often leading to loss of mobility, osteoporosis, chronic fatigue, and chronic pain. Aging-related issues have also been identified in aging persons with Prader-Willi syndrome, Williams syndrome, and fragile X syndrome.⁷ Research on the aging process of adults with autism spectrum disorders has largely been overlooked but may be stimulated by attention from the increased prevalence of autism spectrum disorders and movement toward a greater focus on life span outcomes. Although an increasing body of literature exists regarding health issues, robust epidemiological and population-level surveillance data are needed to identify the prevalence of aging adults with ID, to characterize their health status, and to determine their unique disease risks and trajectories.

There have been previous initiatives to improve the general health of persons with ID. The 2002 report from the US Surgeon General's Conference on Health Disparities and Mental Retardation entitled "Closing the Gap: A National Blueprint to Improve the Health of Persons With Mental Retardation" set forth an ambitious agenda to improve the health of individuals with ID.⁸ The report highlighted disparities in health status, access to care, and health care quality and called attention to the lack of training of physicians and other health care professionals in the needs of individuals with ID across the life span. Nearly a decade later, progress is slow, and efforts affecting the well-being of older adults are even more marginal. Furthermore, there is poor coverage of health promotion and preventive care programs targeted specifically for older adults with lifelong disabilities.

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The unprecedented increase in this aging population requires corresponding increases in training and preparation of health care professionals to meet the needs of adults with ID. While this concept was put forth in the 2002 surgeon general's report,⁸ standard US medical education, continuing medical education, and postgraduate training still lag far behind this goal. As new longevity milestones are achieved in adults with ID, issues related to ID are still not commonly presented in the context of a life span, instead remaining largely the domain of pediatrics or genetics curricula in medical schools. There is a dearth of US studies on programs to improve clinician training on ID,⁸ and the modest extant literature regarding clinician preparation indicates inadequate or absence of formal training on ID.⁹ Currently, there is no curriculum requirement for US medical schools specifically to teach competency in the provision of care to persons with ID. Not surprisingly, many physicians are ill prepared to recognize symptoms or appropriately examine patients who have the physical limitations, communication difficulties, or behavioral issues that often coexist in persons with ID. This often results in unsatisfactory clinical consultation, poor rapport, and inappropriate or suboptimal treatment choices. The addition of geriatric health concerns further disenfranchises this vulnerable population by increasing the medical complexity of new comorbidity that is superimposed on numerous lifelong comorbidities. Many adults with ID face considerable difficulty in locating primary care physicians. In fact, numerous pediatricians provide care to patients with ID long after the transition to adult medical services should have occurred. Moreover, adults with ID who live in supervised residential settings experience frequent turnover of clinical staff, and the lack of continuity of care may result in failure to recognize emerging health issues. In addition, the presence of outdated stigmas and stereotypes regarding persons with ID persist. A 2005 surgeon general report¹⁰ emphasized fostering changes in attitude by health care professionals toward individuals with disabilities, especially with regard to upholding their value and dignity.

Aging adults with ID can no longer be forgotten or ignored. Medical educators should provide content knowledge of life span medical issues along with practical guidance on facilitating communication during clinical consultation. In the coming decades, the aging population will continue to challenge the health care system by its increasing size and heterogeneity, and this overlooked segment of

older adults with ID must be brought into the collective consciousness. Even though older adults with ID have medically complex needs, they remain more disadvantaged, compared with the general aging population, for having their health care concerns appropriately met. Physicians and other health care professionals need to embrace the challenge and rewards that older adults with ID present because, fundamentally, this is the first step needed to reduce the disparities in health that will otherwise continue to increase.

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